Module 5 Stigma and Discrimination Related to MTCT

Total Time: 180 minutes (120 minutes if alternative exercise 5.3 is used rather than the PLWHA panel)

SESSION 1 Introduction to the Concepts of Stigma and Discrimination and International Human Rights

Activity/Method	Resources Needed	Time
Exercise 5.1: Labels interactive game	Notecards or sheets of 8.5" x 11" or A4 paper (one per person participating in the interactive game) Tape	60 minutes

SESSION 2 Values Clarification (Individual Perspective)

Activity/Method	Resources Needed	Time
Exercise 5.2 Examples of stigma and discrimination: large group discussion	None, other than those listed below	30 minutes

SESSION 3 Dealing with Stigma and Discrimination in Healthcare Settings and Communities

Activity/Method	Resources Needed	Time
Exercise 5.3 PLWHA Panel *or*	See Appendices 5-B & 5-C. Note: preparation for the PLWHA Panel should begin about 1 month before the training. Index card or pieces of paper for questions Basket or box	90 minutes
Alternative Exercise 5.3 Stigma and discrimination: case study	See Appendix 5-D. Copies of Case Study for participants	30 minutes

Also have available the following:

- Overheads or PowerPoint slides for this Module (in Presentation Booklet)
- Overhead or LCD projector, extra extension cord/lead
- Flipchart or whiteboard and markers or blackboard and chalk
- Pencil or pen for each participant

Relevant Policies for Inclusion in National Curriculum
Session 1 ▪ National policies on discrimination, equal rights, and human rights ▪ National policies on discrimination, equal rights, and human rights relevant to people with HIV ▪ Local or national policies regarding patient rights within PMTCT and ANC services

The *Pocket Guide* contains a summary of Sessions 1 and 3.

SESSION 1 Introduction to the Concepts of Stigma and Discrimination and International Human Rights

Advance Preparation

Prepare for Exercise 5.1 Labels interactive game by writing on a note card (or piece of paper) a "label" for a person who is HIV-infected and could be stigmatised or stereotyped. Prepare enough "labels" so that each participant receives one. Write the labels large enough that participants are able to see them across the room. Labels could include:

- Man with HIV infection
- Sex worker
- Child with HIV infection
- Government official
- Woman with HIV
- Drug user
- Clergy with HIV infection
- Housewife with HIV infection
- Gay man
- Gay woman
- Mother who is HIV-positive

On the remaining note cards or pieces of paper, write generic labels of people not usually associated with HIV/AIDS-related stigma or stereotyping (for example, doctor, nurse, healthcare worker, or training participant).

Total Session Time: 60 minutes

Trainer Instructions

Lead the group through the following exercise. It is recommended that the facilitator participate in this exercise.

Note This exercise works best if started immediately prior to introducing the module, preferably either as participants return from a lunch or tea/coffee break or first thing in the morning, depending on the time of day.

Exercise 5.1: Labels interactive game	
Purpose	To help recognise the role of stereotypes in stigma.
Duration	20 minutes
Introduction	As each participant enters the room, attach—by tape or safety pin—a "label" on his or her back (without letting the participant see the label). Explain that each person has a label. During this exercise, the participants should behave toward each other as society might treat a person with the label each person is wearing.
Activities	▪ Ask the group to mingle and chat with each other, reacting to others according to the label they are wearing, but without telling them what the label is. ▪ After 5 to 7 minutes, ask the group to sit in their seats.

Debriefing	Start the discussion by asking the following questions**:** ▪ Who can guess what their label is? ▪ How did it feel to be treated in a stereotyped way? ▪ What was the experience like for you? ▪ Were you puzzled or surprised by how you were treated? After the initial discussion, ask the group to take the labels off their backs and look at them. Ask the group to identify specific ways to combat stereotypes and help decrease stigma in their clinical settings. Write the participants' suggestions on the flip chart, whiteboard, or blackboard. Encourage each person to "de-role" by stating their name and something positive about themselves.

Trainer Instructions

Slides 1, 2 and 3

Review module objectives.

Explain that upon completion of this module, the participants will be able to:

- Define and identify HIV/AIDS-related stigma and discrimination.
- Better understand international and national human rights issues.
- Clarify personal values and attitudes with regard to HIV/AIDS prevention and care.
- Know how to address stigma and discrimination in the context of providing PMTCT services.

Trainer Instructions

Slide 4

Introduce the concepts of stigma and discrimination, as discussed on the next page.

Introduction to the concepts of stigma and discrimination

HIV/AIDS is not only the greatest health challenge of our time, but it is also the greatest human rights challenge. Those aware they are HIV-infected shoulder the twin burdens of stigma and discrimination. Fear of becoming infected underlies stigma and discrimination, which remain major impediments to preventing HIV transmission and providing treatment, care, and support to people who are HIV-infected and their families.

HIV/AIDS-related stigma is increasingly recognised as the single greatest challenge to slowing the spread of the disease at the global, national, and community/provider level.

The most effective responses to the HIV/AIDS epidemic are those that work to prevent the stigma and discrimination associated with HIV, and to protect the human rights of people living with HIV and those at risk of infection.

What is stigma?

Stigma refers to unfavourable attitudes and beliefs directed toward someone or something.

HIV/AIDS-related stigma

HIV/AIDS-related stigma refers to all unfavourable attitudes and beliefs directed toward people living with HIV/AIDS (PLWHA) or those perceived to be infected, and toward their significant others and loved ones, close associates, social groups, and communities.

Stigmatising attitudes are often directed not only toward the person with HIV, but also toward behaviours believed to have caused the infection. Stigma is particularly pronounced when the behavior linked to the origin of a particular disease is perceived to be under the individual's control, such as prostitution or injection drug use.

People who often are already socially marginalised—poor people, indigenous populations, men who have sex with men, injection drug users, and sex workers—frequently bear the heaviest burden of HIV/AIDS-related stigmatisation. People who are HIV-infected are often assumed to be members of these groups, whether they are or not.

Make These Points

- Emphasise that HIV/AIDS stigma is often more severe than stigma associated with other diseases.
- HIV transmission is believed to be under the control of the individual, so unlike tuberculosis, for example, people with HIV may be blamed for their illness.
- In many settings, people who are affected by HIV are the same people who are already marginalised in society, ie, poor people and indigenous people.

Trainer Instructions

Slides 5 and 6

Discuss discrimination as well as the difference between stigmatisation and discrimination, as described in the box on the next page.

What is discrimination?

Discrimination is the treatment of an individual or group with partiality or prejudice. Discrimination is often defined in terms of human rights and entitlements in various spheres, including healthcare, employment, the legal system, social welfare, and reproductive and family life.

Stigmatisation and discrimination

Stigmatisation reflects an attitude, but *discrimination* is an act or behaviour. Discrimination is a way of expressing, either on purpose or inadvertently, stigmatising thoughts.

Stigma and discrimination are linked. Stigmatised individuals may suffer discrimination and human rights violations. Stigmatising thoughts can lead a person to act or behave in a way that denies services or entitlements to another person.

Stigma and discrimination have been documented in association with other disfiguring or incurable infectious diseases, including tuberculosis, syphilis, and leprosy. However, HIV/AIDS-related stigma appears to be more severe than the stigma associated with other life-threatening infectious diseases.

Three phases of the HIV/AIDS epidemic

Three phases of the HIV/AIDS epidemic have been identified: the epidemic of HIV; the epidemic of AIDS; and the epidemic of stigma, discrimination, and denial. The third phase is as central to the global AIDS challenge as the disease itself.

Examples of discrimination

- A person with HIV is denied services by a healthcare worker.
- The wife and children of a man who recently died of AIDS are ostracised from the husband's familial home or village after his death.
- An individual loses his job because it becomes known that he/she is HIV-infected.
- A person finds it difficult to get a job once it is revealed that he/she is HIV-infected.
- A woman who decides not to breastfeed is assumed to be HIV-infected and is ostracised by her community.

Trainer Instructions

Slide 7

Discuss international human rights and HIV-related stigma, using the information below.

Make These Points

Summarise any pertinent national/local laws related to human rights and HIV-related stigma or discrimination.

International human rights and HIV-related stigma and discrimination

Freedom from discrimination is a fundamental human right founded on principles of natural justice that should be universally applied to people everywhere. According to recent United Nations Commission on Human Rights resolutions, "discrimination on the basis of HIV/AIDS status, actual or presumed, is prohibited by existing human rights standards." In other words, discrimination against PLWHA or people thought to be infected is a clear violation of human rights.

The forms of stigma and discrimination faced by people with HIV/AIDS are varied and complex. Individuals are stigmatised and discriminated against not only because of their HIV-positive status but also because of what that status implies. UNAIDS-sponsored research in India and Uganda showed that women with HIV/AIDS may be doubly or triply stigmatised—as women, as PLWHA, as the spouse of a person who is HIV-infected, or the widow of a person who died of AIDS. A woman may face additional stigmatisation as a "woman who is HIV-infected and is pregnant and/or has children." For example, she may be treated poorly or denied medical and psychosocial support services.

Trainer Instructions

Slides 8 and 9

Discuss the role of the PMTCT programme in protecting, respecting, and fulfilling human rights as described in the box below.

Make These Points

- Review the specific rights listed below one at a time and invite participants to comment on popular cultural views on each of these rights.
- Explain that gender relationships in a culture have an impact on human rights and on vulnerability to becoming infected with HIV.

Protect, respect, and fulfill human rights in relation to HIV

- All women and men, irrespective of their HIV status, have a right to determine the course of their sexual and reproductive lives and to have access to information and services that allow them to protect their own and their family's health.
- Children have a right to survival, development, and health.
- Women and girls have a right to information about HIV/AIDS and access to the means of protecting themselves against HIV infection.
- Women have the right to access to HIV testing and counselling and to know their HIV status.
- Women have a right to choose not to be tested or to choose not to be told the result of an HIV test.
- Women have a right to make decisions about infant feeding, on the basis of full information, and to receive support for the course of action they choose.

A summary of the International Guidelines on HIV/AIDS and Human Rights, as adopted by the Second International Consultation (July 2002), can be found in Appendix 5-A. These 12 guidelines urge governments to review laws, policies, systems, and practices to ensure protection of the human rights of people at-risk for or infected with HIV.

SESSION 2 Values Clarification (Individual Perspective)

Advance Preparation

Review the examples of stigma and discrimination provided for this session in Exercise 5.2 and consider local examples that could be included in this list.

Total Session Time: 30 minutes

Trainer Instructions

Slides 10, 11 and 12

Discuss how stigma is expressed, using the information below.

The face of stigma

HIV/AIDS-related stigma is complex, dynamic, and deeply ingrained. The points below may provide PMTCT programmes with a framework for developing and implementing interventions to address HIV/AIDS-related stigma and discrimination.

Attitudes and actions are stigmatising.

People are often unaware that their attitudes and actions are stigmatising. A word, action or belief may be unintentionally stigmatising or discriminatory toward an individual who is HIV-infected. People often exhibit contradictory beliefs and behaviours. For example, consider the following:

- A person who is opposed to stigmatisation or discrimination may simultaneously believe that PLWHA indulge in immoral behaviours, deserve what they get, or are being punished by God for their sins.
- A person who claims to know that HIV cannot be transmitted through casual contact may still refuse to buy food from a vendor who is HIV-infected or allow his family to use utensils once used by a PLWHA.

Choice of language may express stigma.

- Language is central to how stigma is expressed. People may not realise that they are stigmatising with their choice of words in referring to HIV disease or PLWHA. One way that language can be stigmatising is in the use of derogatory references to those with HIV/AIDS. In some countries people refer to HIV, not by name, but rather indirectly as, for example, "that disease we learned about" and refer to PLWHAs as “walking corpse” and “expected to die”.

Lack of knowledge and fear foster stigma.

Knowledge and fear interact in unexpected ways that allow stigma to continue. Although most people have some understanding of HIV transmission and prevention, many lack in-depth or accurate knowledge about HIV. For example, many do not understand the difference between HIV and AIDS, how the disease progresses, the life expectancy of PLWHA, or that HIV/AIDS-related opportunistic infections (such as tuberculosis) are treatable and curable. Others equate an HIV-positive test result with imminent death. The fear of death is so powerful that many people will avoid individuals suspected to have HIV—even though they know that HIV is not transmitted through casual contact.

Shame and blame are associated with HIV/AIDS.

Sexuality, morality, shame, and blame are associated with HIV/AIDS. Stigmatisation often centres on the sexual transmission of HIV. Many people assume that individuals who are HIV-infected must have been infected through sexual activities deemed socially or religiously unacceptable. People who are HIV-infected are often presumed to be promiscuous, careless, or unable to control themselves, and therefore responsible for their infection.

Stigma makes disclosure more difficult.

Disclosure, the sharing of HIV status with others, is advocated but often difficult—and uncommon—in practice. Most people believe that disclosure of HIV infection should be encouraged. Yet many people infected with HIV avoid disclosing their HIV status for fear that doing so will subject them to unfair treatment and stigma. Some of the benefits of disclosure are the following:

- Disclosure can encourage partner(s) to be tested for HIV.
- Disclosure can help prevent the spread of HIV to partner(s).
- Disclosure allows individuals to receive support from partner(s), family, and/or friend(s).

Stigma can exist even in caring environments.

Care and support can coexist with stigma. Caregivers who offer love and support to family members living with HIV/AIDS may also exhibit stigmatising and discriminatory behaviour (such as blaming and scolding). In many cases, the caregivers don't recognise this behaviour as stigmatising.

- Stigmatising attitudes exist even among those individuals, communities and health-care workers who are opposed to HIV/AIDS-related stigma.
- People can have both correct and incorrect information about HIV at the same time. For example, an individual's understanding of the routes of HIV transmission may be accurate in some respects but inaccurate in others.
- People express both sympathetic and stigmatising attitudes toward PLWHA.
- Families that provide genuine and compassionate care may sometimes stigmatise and discriminate against a family member with HIV/AIDS.

Trainer Instructions

Lead the participants in a discussion of examples of stigma and discrimination in a variety of settings as described below.

Exercise 5.2 Examples of stigma and discrimination: large group discussion	
Purpose	To encourage participants to consider examples of stigma and discrimination in their own settings.
Duration	10 minutes
Introduction	Start the discussion by suggesting that many of us have either witnessed or heard stories about cases of stigmatising and discriminatory treatment of PLWHA. Explain that this exercise provides an opportunity to share some of those stories.

Activities	▪ **Show Slide 13.**
	▪ Ask the participants to give examples of stigmatising or discriminatory messages or attitudes in the *media* (newspapers, television, or radio programmes). Give participants a couple of minutes to supply three or four examples. If participants have difficulty citing examples in the media category, offer the examples on the next page and move on to the next category.
	▪ Ask the participants for examples of stigmatisation or discrimination they may have witnessed in *healthcare settings*. Again, if you need to get the discussion restarted, refer to examples for this category in the material below.
	▪ Ask the participants for examples of stigmatisation or discrimination they may have witnessed in the *workplace*.
	▪ While still showing **Slide 13**, ask the participants for examples of stigmatisation or discrimination that they have witnessed
	  ▪ In the context of religion
	  ▪ In the family or community
	▪ Again, give the participants a few minutes to supply three to four examples in each category.
	▪ When participants offer examples that repeat patterns or themes mentioned in the discussion of earlier categories, you can close the discussion.

Debriefing	▪ Conclude by showing and explaining the effects of stigma as described in the next section.

Make These Points

- Stigma and discrimination may be found in all aspects of society. Review the categories listed below and compare with the lists developed by participants during Exercise 5.2.

Examples of stigmatisation and discrimination

In the media

- Suggesting in the media that there are specific groups of people with HIV who are guilty (such as sex workers or injection drug users) whereas others (such as infants) are innocent
- Depicting HIV/AIDS as a death sentence, which perpetuates fear and anxiety, and labels HIV as a disease that cannot be managed like any other chronic disease
- Using stereotypical gender roles, which may perpetuate women's vulnerability to sexual coercion and HIV infection

In health services

- Refusing to provide care, treatment, and support to PLWHA
- Providing poor quality of care for PLWHA
- Violating confidentiality
- Providing care in stand-alone settings (such as clinics for sexually transmitted infections) that further stigmatise and segregate PLWHA
- Using infection-control procedures (such as gloves) only with patients thought to be HIV-positive, rather than with all patients
- Advising or pressuring PLWHA to undergo procedures, such as abortion or sterilisation, that would not be routinely suggested for others

In the workplace

- Requiring testing before employment
- Refusing to hire people who are HIV-infected and HIV-affected
- Mandating periodic HIV testing
- Being dismissed because of HIV status
- Violating confidentiality
- Refusing to work with colleagues who are HIV-infected because of fear of contagion

In the context of religion

- Denying participation in religious/spiritual traditions and rituals (such as funerals) for PLWHA
- Restricting access to marriage for PLWHA
- Restricting participation of PLWHA in religious activities

In the family and local community

- Isolating people who are HIV-infected
- Restricting participation of PLWHA in local events
- Refusing to allow children who are HIV-infected or HIV-affected in local schools
- Ostracising of partners and children of PLWHA
- Using violence against a spouse or partner who has tested HIV-positive
- Denying support for bereaved family members, including orphans

Trainer Instructions

Slide 14

Discuss the effects of stigma, using the information below.

Effects of stigma

Stigma is disruptive and harmful at every stage of the HIV/AIDS continuum, from prevention and testing to treatment and support. For example, people who fear discrimination and stigmatisation are less likely to seek HIV testing while persons who have been diagnosed may be afraid to seek necessary care. PLWHA also may receive suboptimal care from workers who stigmatise them.

- Stigma may reduce an individual's choices in healthcare and family/social life.
- Stigma may limit access to measures that can be taken to maintain health and quality of life.

HIV/AIDS-related stigma fuels new HIV infections.

- Stigma may deter people from getting tested for the disease.
- Stigma may make people less likely to acknowledge their risk of infection.
- Stigma may discourage those who are HIV-infected from discussing their HIV status with their sex partners and/or those with whom they share needles.
- Stigma may deter PLWHA from adopting risk-reduction practices that may label them as HIV-infected.

Stigma and discrimination can lead to social isolation.

A study in South Africa found that both men and women who are HIV-infected face social isolation, rumours and gossip, ejection from the home, rejection by the community, and verbal abuse. One person in the study stated, "There are those who will tell you face-to-face that you are no longer needed in their friendship, those who will just isolate you." Another said, "People make jokes about HIV-infected people and point fingers at them."

Stigma and discrimination can limit access to services.

HIV/AIDS-related stigma and discrimination may discourage individuals from contacting health and social services, thereby increasing the risk of transmission to partners or children. In many cases, those people most in need of information, education and counselling will not benefit from these services—even when they are available.

Secondary stigma (stigma by association)

The effects of stigma often extend beyond the infected individual to stigma by association also known as secondary stigma. **Secondary stigma** is evidenced in statements like "If I sit near someone with AIDS, others will think that I have AIDS too." HIV/AIDS programme social workers and peer educators in South Africa reported that they were sometimes stigmatised because of their work with PLWHA.

Stigma and PMTCT services

Stigma and discrimination pose distinct challenges to the delivery of PMTCT services. Notably, in many areas women may avoid replacement feeding because they know that they will be labelled as HIV-infected if they are not breastfeeding. The children of mothers who participate in PMTCT programmes may experience secondary stigmatisation because people assume that they are HIV-infected.

Trainer Instructions

Slide 15

Discuss the consequences of stigma in the PMTCT programme setting.

Consequences of stigma in PMTCT programmes

- Discourages women from accessing antenatal care services
- Prevents people from receiving HIV testing and, as a result, PMTCT services
- Discourages women from discussing their HIV tests and disclosing results to their partner(s)
- Discourages women from accepting PMTCT interventions eg, ARV teatment and prophylaxis
- Discourages the use of recommended PMTCT safer infant-feeding practices (replacement feeding or early cessation of breastfeeding)

SESSION 3 Dealing with Stigma and Discrimination in Healthcare Settings and Communities

Advance Preparation

Prepare for Exercise 5.3 PLWHA Panel:

- See Appendix 5-B for information on planning and hosting a PLWHA panel.
- When possible, about 1 month before the training course, contact an AIDS service organisation to recruit 1 to 4 PLWHA who have publicly disclosed their HIV status and who are comfortable and self-confident talking about it.
- Brief the panellists about the training course, its objectives, and the participants (who they are, their job positions, their attitudes toward people with HIV).
- Advise the panellists that they may cancel their commitment at any time and that they should not feel obligated to answer questions that make them feel uncomfortable.
- Develop a question/interview guide. A sample guide appears in Appendix 5-C at the end of this module. If you use the sample guide, be sure to adapt it to local expectations.

Note: If panellists cannot be recruited, there is an *Alternative exercise 5.3 Stigma and discrimination: case study* in Appendix 5-D. If using the alternative exercise:

- Adapt the case study so the characters and setting are more representative of participants' workplace(s). If necessary, interview PMTCT staff to generate a case study based on actual examples of stereotyping and stigma in the community.

Total Session Time: 90 minutes for the PLWHA Panel (30 minutes if using the Alternative Exercise 5.3)

Trainer Instructions

Slides 16 and 17

Introduce the concept that each of us has a role in reducing the stigma and discrimination directed to PLWHA. Interventions in which each of us can participate or support can be implemented on many levels in a variety of settings.

Addressing stigma in PMTCT programmes

To increase participation in PMTCT services, programmes should implement interventions that address HIV/AIDS-related stigma. These efforts should occur at all levels:

- National
- Community, social, and cultural
- PMTCT site
- Individual

Stigmatisation is a social process that must be addressed on the community level. Because PMTCT healthcare workers and patients are influenced by the community and culture in which they live, it is essential that PMTCT programmes collaborate with the community to address HIV/AIDS-related stigma and discrimination. This session presents various interventions that may be implemented by PMTCT programmes and the communities they serve. These interventions cover a wide range of activities; each programme should set priorities for initial interventions and phase in additional efforts over time.

Trainer Instructions

Slides 18 and 19

Discuss efforts to address HIV/AIDS-related stigma on the national level, as described below.

National level

High-level political support for national HIV/AIDS initiatives and policies that address the human rights of PLWHA is important. High-ranking politicians and other high-profile individuals, such as television stars and musicians, may serve as leaders and role models in these efforts. It is essential to secure both formal and informal support at the national level, without which local initiatives will struggle to succeed.

National level activities that affect HIV/AIDS and PMTCT-related legislation and healthcare practice may include the following:

- Support and advocate legislation that protects the rights of PLWHA as human beings and patients.
- Support legislation that protects the legal rights of women in health care, education, and employment.
- Advocate for laws supporting anti-discrimination policies—at the administrative, budgetary, and judicial levels.
- Support national efforts to scale-up treatment of HIV with antiretroviral (ARV) drugs for those in need.
- Advocate for quality treatment programmes for people with drug addictions.
- Involve consumers in national advocacy and elicit their help in designing, developing and evaluating programmes and policies.

- Advocate for sufficient funding for PMTCT services and staff training.
- Publicise programme successes by inviting national and local politicians to clinics to see how PMTCT programmes work.
- Ensure that the problems—and solutions—are communicated to those who have the power and authority to address them when issues require national level solutions (such as national shortages in ARV prophylaxis and shortages in the supply of breastmilk substitutes).
- Educate national leaders about the importance of PMTCT programmes.
- Encourage national leaders to serve as role models in their professional and personal lives.
  - Encourage leaders to hire staff that are HIV-infected.
  - Encourage leaders to praise the good work of PMTCT clinics to the public and to the press.
  - Encourage leaders to visit an AIDS service organisation.
  - Encourage leaders to speak out against emotional, verbal and physical abuse directed at women infected with HIV.
  - Remind leaders to promote funding of HIV/AIDS care programmes.
  - Suggest that leaders be tested for HIV.

Trainer Instructions

Slides 20 and 21

Discuss community-level interventions, as described below.

Make These Points

- Communication about HIV/AIDS among members of a community is essential for normalising HIV and reducing stigma.
- Discuss the concept "Silence = Death" and invite participants to identify particular people in their communities who may be able to influence community perspectives on HIV/AIDS in either their personal or professional roles.

Community level

HIV/AIDS education and training

Provide HIV/AIDS education and training to members of the community, especially key opinion leaders, traditional birth attendants, traditional healers, healthcare staff in referring organisations, religious leaders, and managers in private industry. Educational and informational initiatives can accomplish the following:

- Increase knowledge about HIV
- Increase awareness of issues faced by PLWHA
- Increase awareness of domestic violence faced by newly diagnosed women
- Communicate, through community leaders, that violence against women is inappropriate, immoral, and/or illegal
- Encourage leaders to make their workplaces HIV-friendly
- Promote PMTCT activities as an integral part of healthcare and HIV/AIDS prevention and treatment
- Educate the community about PMTCT interventions (including ARV prophylaxis and safer infant-feeding practices), stressing the importance of community and family support in PMTCT initiatives
- Increase referrals to and from PMTCT services
- Secure the involvement of community members and PLWHA in organising, developing, and delivering HIV education, prevention, and support programmes.

Community awareness of PMTCT interventions

Increase community awareness of PMTCT interventions to help men and women recognise their roles and responsibilities in protecting themselves and their families against HIV infection.

Greater community awareness should also strengthen social support for the partner, extended family, and community. The people who cope the best with their HIV infection tend to be those who have social and family support.

For example, families and close friends can help remind those with HIV infection take their medicines on time. If the person with HIV is pregnant, family members often help ensure that she gives birth at the health centre and that she takes her ARV prophylaxis. They can also help ensure that the baby receives ARV prophylaxis and support infant-feeding methods that reduce the risk of HIV transmission.

Community partnerships

Build partnerships with churches, schools, and social or civic organisations when developing PMTCT services. Promoting PMTCT services in community organisations will enhance sustainability and will help develop a broad base of support for the PMTCT initiative.

Other community level interventions

Additional community level interventions may include the following:

- Facilitating the exchange of information and ideas among healthcare professionals and other caregivers of PLWHA through roundtable case discussions and social activities
- Providing input into curricula for students in healthcare professions (nurses, midwives, physicians)

PLWHA involvement

Invite PLWHA to become involved in national and local initiatives. Doing so will empower them. It will also help the community realise that PLWHA are not the cause of the HIV/AIDS problem but are part of the solution. Involving PLWHA in initiatives will:

- Help PLWHA gain and practise life skills in communication, negotiation, conflict resolution, and decision-making, which empowers them to challenge HIV/AIDS-related stigma and discrimination
- Encourage PLWHA to join together to challenge stigma and discrimination.
- Promote the active involvement of PLWHA in national and local activities to foster positive perceptions of people living with HIV
- Support the establishment of PLWHA organisations and networks, including those that enable people to demand recognition and defend their rights

Training programmes for PLWHA

Develop and implement training programmes for PLWHA to help them advocate for their rights and take an active role in their own healthcare. By participating in interventions (such as PMTCT services or HIV prevention and care education) as volunteers, advisors, board members, or paid employees, PLWHA will demonstrate their ability to remain productive members of the community. This normalises the experience of living with HIV infection.

Trainer Instructions

Slides 22, 23 and 24

Discuss interventions at the PMTCT programme level, using the information below.

PMTCT programme level

PMTCT services should be integrated into and supported by the local community. Although PMTCT programmes often reflect the communities in which they are based, they can take the lead in challenging long-held community perceptions and practices, including stigmatisation of and discrimination against PLWHA and PMTCT patients.

Integration of PMTCT interventions into antenatal care (ANC) services

Integrate all PMTCT interventions into mainstream antenatal care (ANC) services for all women. Offer voluntary HIV testing and education to all clinic attendees, regardless of their perceived HIV risk. Mainstreaming (or bundling) HIV services with routine ANC services helps normalise HIV/AIDS.

Participation of partners

Develop ways to increase the participation of partners in all aspects of PMTCT services. Educate partners about PMTCT interventions (including ARV treatment and prophylaxis and modified infant-feeding practices) and stress the importance of partner testing, partner and family support in PMTCT, particularly with respect to ARV prophylaxis and infant feeding.

As an example, two sites in Kenya invited men to visit the PMTCT clinic for counselling and testing and PMTCT education designed specifically for a male audience. As a result of these interventions, the programme:

- Improved spousal communication about PMTCT
- Increased HIV testing among male partners of PMTCT patients
- Increased HIV test disclosure rates for both partners

Educational sessions

Offer group or individual education sessions (onsite and offsite), which can help draw attention to the role that partners play in HIV transmission and reduce stigmatisation of women.

- Couples counselling offers another opportunity to reduce the blame that can be directed at women and emphasise the couple's shared responsibility in PMTCT.

When male partners do not normally attend ANC clinics, PMTCT programmes should reach out to them in male-friendly settings (eg workplaces, barber shops, bars, cafeterias).

Healthcare worker training

Educate and train healthcare workers. The success or failure of a PMTCT programme depends upon the attitudes, skills, and experience of its employees. Training healthcare workers at all levels (manager, nurse, midwife, physician, social worker, counsellor and outreach worker) is critical to the success of PMTCT initiatives. Employee training should include:

- Complete and accurate information about the transmission of HIV and the risks factors for infection
- Activities that address HIV/AIDS-related stigma

Understanding the perspectives and rights of PLWHA and their families

In addition to presenting information, it is important for educational initiatives to address employee attitudes, correct misinformation, and assess skills.

Educate healthcare workers to better understand the perspectives and rights of PLWHA and their families. Without adequate HIV-related education, staff may have irrational fears, practise inappropriate care, and use stigmatising language and behaviour. Accordingly, training healthcare workers to reduce stigmatising behaviour will address assumptions about the educational, social, economic, and class status of PLWHA and encourage participants to examine their prejudices.

During training activities, strive to increase awareness of the language used to describe HIV/AIDS and PLWHA. The training should include:

- Exercises designed to encourage participants to explore personal attitudes and prejudices that might lead them to use stigmatising language
- Summaries of institutional confidentiality, anti-discrimination, and infection control policies as well as the consequences of policy breaches and grievance procedures

If possible, at least one member of the PMTCT staff should have special training in HIV testing and counselling and infant feeding. If possible, a member of the staff should also receive additional training in screening, counselling, and referral of women experiencing or at risk of domestic violence.

Infection control

Ensure infection control by providing all healthcare workers with the necessary equipment and supplies (including high-quality, well-fitting gloves) needed to adhere to infection control policies and prevent transmission of HIV in the workplace (See *Module 8: Safety and Supportive Care in the Work Environment*). Apply universal precautions to all patients regardless of assumed or established HIV status.

Patient confidentiality

Safeguard patient confidentiality by developing policies and procedures and establishing discrete plans for implementing them. Confidentiality in healthcare facilities is also discussed in *Module 6, HIV Testing and Counselling for PMTCT.* Confidentiality policies should include:

- Directions on how to record and securely store patient information
- Assurances that neither PLWHA nor their medical files (whether paper or electronic) will be labelled to reveal HIV status
- Assurances that all patient consultations, from the initial contact with the receptionist to the consultation with the physician, will respect personal information

The confidentiality policy should emphasise that all personal conversations and consultations should take place in private settings. It should also establish:

- Policies for disclosure of medical information to a patient's family (which should only occur with the patient's informed consent)
- Policies for addressing and disciplining breaches of confidentiality
- Steps patients can take to address breaches of confidentiality
- Requirements for staff confidentiality training
- The critical importance of confidentiality and the effects that breaches may have on individual patients and the PMTCT service as a whole

Role models

Encourage PMTCT staff to serve as role models by treating PLWHA just as they would treat patients assumed to be HIV-negative. Healthcare workers are role models, and their attitudes toward PLWHA are often imitated in the community. Staff should aim to normalise all casual contacts with PLWHA.

Knowing the local community

Get to know the local community, which will help to identify local HIV-related stereotypes and rumours. Ensure that these misconceptions are addressed at appropriate times during PMTCT services. In many cultures, for example, women who bottle-feed or cup-feed their infants may be labelled as HIV-infected. In such cultures, PMTCT workers should address this stereotype during counselling and educational sessions and emphasise the importance of safer infant-feeding practices for reducing MTCT.

Women's rights

Advocate for women's rights. Ensure that women diagnosed with HIV are educated about their rights and know where to turn for help, including legal advice, to challenge discrimination and stigmatisation.

Peer and community support

Facilitate peer and community support. Recognise that support groups in the ANC setting provide an opportunity for pregnant women who are HIV-infected to share experiences and be linked to other support services. PMTCT programmes can facilitate such support groups by:

- Supporting mentoring programmes. South Africa's Mothers-to-Mothers-to-Be is a mentorship programme for pregnant women who are HIV-infected. Mothers who are HIV-infected and have recently given birth return to the ANC facility as mentors to educate, counsel, and support pregnant women who are HIV-infected.
- The mother-mentors share personal experiences to encourage adherence to treatment, help with making infant-feeding decisions, and assist with negotiating care and support services. The mentoring has resulted in better understanding and greater acceptance of interventions to reduce MTCT.
- Encouraging peer support. Encourage PLWHA to pair up with another person—HIV-positive or negative—who can provide friendship, companionship, advice, or mentoring.

Involving PLWHAs in PMTCT programmes can help address stigma and discrimination issues and promote better understanding of and support for those with HIV infection.

Counselling and education for PLWHA

Counselling and education for PLWHA, provided either within the PMTCT service or through linkages to other services, can address HIV-related stigma in a number of ways:

- Counsellors can encourage, empower, and support PLWHA to disclose their HIV status to family and eventually to friends. As more people disclose their HIV status, PLWHA become more visible, which encourages community acceptance of PLWHA.
- Counsellors should be trained to ask all their patients, particularly women, about domestic violence. Women found to be at risk of physical, verbal, or emotional abuse should receive support and referrals.

Trainer Instructions

Slide 25

Discuss the responsibilities of PMTCT Programme Managers as described below.

Make These Points

- Early involvement of supervisory staff in the PMTCT programme is essential for reducing stigma and discrimination.
- The commitment of the programme manager is key to effectively implementing policies that will facilitate access to and use of PMTCT programmes.

Role of PMTCT programme managers

It is vital for PMTCT programme managers to ensure that policies and procedures are in place to protect individuals from discrimination and stigmatisation. PMTCT programme managers also play an important role in the development, implementation, and enforcement of confidentiality policies. Some of the actions managers can take to reduce stigma and discrimination include the following:

- Maintain policies against discriminatory recruitment and employment practices.
- Support workers who are HIV-infected so they continue to perform optimally in their positions.
- Offer flexible hours and access to healthcare services.
- Establish policies that guarantee all patients equal treatment regardless of HIV status.
- Ensure procedures for reporting discrimination and protocols for disciplining staff who breach the non-discrimination policy.
- Promote the programme's policies to staff and patients, and remind patients that they can file a complaint if they feel they have been the target of discrimination.

In addition, programme managers can also help ensure that all staff follow universal precautions, which may reduce the stigma associated with fear of infection. The manager can:

- Update the facility's infection control policy as necessary.
- Ensure ongoing access to infection control supplies and equipment.
- Make sure that staff members apply universal precautions at all times.
- Discipline employees who breach the universal precautions policy.
- Make post-exposure prophylaxis (PEP) accessible to staff in cases of accidental exposure to blood and body fluids as per national/local policy where it exists.

Trainer Instructions

Facilitate the PLWHA panel, using Appendices 5-B and 5-C as guides.

*Note: I*f a panel cannot be recruited the *Alternative Exercise 5.3 Stigma and discrimination case study* is available in Appendix 5-D.

Exercise 5.3 PLWHA Panel	
Purpose	To give PLWHA an opportunity to share their experiences in the healthcare system and to help educate healthcare workers.
Duration	60 minutes
Introduction	Tell the group that you have invited a panel of PLWHA to speak today. Explain that discussing PMTCT and HIV/AIDS care from the perspective of patients may help healthcare workers offer more compassionate care.

Activities	▪ As noted in Appendix 5-B, this panel presentation should be facilitated by an experienced moderator. ▪ The moderator should start the panel presentation after the panellists are comfortably seated. Panellists should sit side-by-side in the front of the training room so they are facing the participants. ▪ The moderator should start the panel presentation by either introducing the panellists or having them introduce themselves (include panellists' names, positions, and agency/organisation). ▪ The moderator may start by asking the panellists questions using an interview/question guide. (A sample of an interview guide is included in Appendix 5-C.) Questions may be posed in any order, and the moderator may ask a single panellist multiple questions before moving on to the next panellist. ▪ The PLWHA should be treated as respected teachers throughout their stay. If the panellists have agreed to a Q&A format, the moderator should ensure that the participants' questions are reasonable, the panellists are comfortable answering them, and the participants remain compassionate and nonjudgemental. ▪ The moderator should make sure the discussion is interesting and stimulating and covers a variety of topics.
Debriefing	Allow the opportunity for both panellists and participants to express thoughts that triggered emotional responses during the discussion. At the end of the session, the moderator should thank the panellists. Panel discussions are emotionally charged and thought-provoking. Following the panel it is important to give participants a short tea break.

Trainer Instructions

Slides 26, 27, 28, 29 and 30

Review the key points of this module, as summarised in the box on the following page.

Module 5: Key points

- While stigmatisation reflects an attitude, discrimination is an act or behaviour.
- Discrimination is often defined in terms of human rights and entitlements in health care, employment, the legal system, social welfare, and reproductive and family life.
- Stigma and discrimination are interlinked. Stigmatising thoughts can lead to discrimination and human rights violations.
- International and national human rights declarations affirm that all people have the right to be free from discrimination on the basis of HIV/AIDS status.
- PMTCT programme staff have a responsibility to respect the rights of all women and men, irrespective of their HIV status.
- HIV/AIDS-related stigmatisation and discrimination may discourage PLWHA from accessing key HIV services. It may also:
  - Discourage disclosure of HIV status
  - Reduce acceptance of safer infant-feeding practices
  - Limit access to education, counselling, and treatment even when services are available and affordable
- PMTCT programme staff can help reduce stigma and discrimination in the health-care setting, in the community, and on the national level.
- Encourage PMTCT staff to serve as role models by treating PLWHA just as they would treat patients assumed to be HIV-negative.
- Involve PLWHAs in every aspect of the PMTCT programme.
- Promote partner participation and community support.

APPENDIX 5-A International Guidelines on HIV/AIDS and Human Rights

GUIDELINE 1:

States should establish an effective national framework for their response to HIV/AIDS, which ensures a coordinated, participatory, transparent and accountable approach, integrating HIV/AIDS policy and programme responsibilities across all branches of government.

GUIDELINE 2:

States should ensure, through political and financial support, that community consultation occurs in all phases of HIV/AIDS policy design, programme implementation and evaluation and that community organisations are enabled to carry out their activities, including in the field of ethics, law and human rights, effectively.

GUIDELINE 3:

States should review and reform public health laws to ensure that they adequately address public health issues raised by HIV/AIDS, that their provisions applicable to casually transmitted diseases are not inappropriately applied to HIV/AIDS and that they are consistent with international human rights obligations.

GUIDELINE 4:

States should review and reform criminal laws and correctional systems to ensure that they are consistent with international human rights obligations and are not misused in the context of HIV/AIDS or targeted against vulnerable groups.

GUIDELINE 5:

States should enact or strengthen anti-discrimination and other protective laws that protect vulnerable groups, people living with HIV/AIDS and people with disabilities from discrimination in both the public and private sectors, ensure privacy and confidentiality and ethics in research involving human subjects, emphasise education and conciliation and provide for speedy and effective administrative and civil remedies.

GUIDELINE 6:

States should enact legislation to provide for the regulation of HIV-related goods, services and information, so as to ensure widespread availability of qualitative prevention measures and services, adequate HIV prevention and care information, and safe and effective medication at an affordable price.

GUIDELINE 7:

States should implement and support legal support services that will educate people affected by HIV/AIDS about their rights, provide free legal services to enforce those rights, develop expertise on HIV-related legal issues and utilise means of protection in addition to the courts, such as offices of ministries of justice, ombudspersons, health complaint units and human rights commissions.

APPENDIX 5-A International Guidelines on HIV/AIDS and Human Rights *(continued)*

GUIDELINE 8:

States, in collaboration with and through the community, should promote a supportive and enabling environment for women, children and other vulnerable groups by addressing underlying prejudices and inequalities through community dialogue, specially designed social and health services and support to community groups.

GUIDELINE 9:

States should promote the wide and ongoing distribution of creative education, training and media programmes explicitly designed to change attitudes of discrimination and stigmatisation associated with HIV/AIDS to understanding and acceptance.

GUIDELINE 10:

States should ensure that government and the private sector develop codes of conduct regarding HIV/AIDS issues that translate human rights principles into codes of professional responsibility and practice, with accompanying mechanisms to implement and enforce these codes.

GUIDELINE 11:

States should ensure monitoring and enforcement mechanisms to guarantee the protection of HIV-related human rights, including those of people living with HIV/AIDS, their families and communities.

GUIDELINE 12:

States should cooperate through all relevant programmes and agencies of the United Nations system, including UNAIDS, to share knowledge and experience concerning HIV-related human rights issues and should ensure effective mechanisms to protect human rights in the context of HIV/AIDS at international level.

Source: OHCHR, UNAIDS. 2002. *HIV/AIDS and Human Rights International Guidelines, Revised Guideline 6: Access to prevention, treatment, care and support.* Geneva, August 2002, pp 10–12.

APPENDIX 5-B Guidelines for PLWHA panels

Exercise 5.3 PLWHA Panel	
Purpose	Learners will gain insight into the psychological and physical effects of HIV infection, the role of health policy, and the grief and loss experienced by survivors of persons who die of HIV/AIDS.
Room Setup	Ensure panellists are comfortable and can be seen and heard by all audience members. Chairs at a skirted table set up on a raised platform may be preferable; podiums may be intimidating for panellists. Ensure each panellist has access to a microphone, if available, and to a glass of water.
Instructions	Several steps are involved in developing a panel of HIV-affected individuals: **Choose a qualified facilitator.** The facilitator (or moderator) must have experience working with and leading groups (eg, a social worker, psychologist, or nurse experienced in caring for PLWHA. Meet with the facilitator at least one week prior to the panel presentation to review the purpose of the exercise and the role of the facilitator. Provide practice questions for the panel and discuss strategies for averting problems. **Obtain suggestions for panellists and respect confidentiality.** When looking for people who would be willing to serve on a PLWHA panel, consult with a local AIDS service organisation's staff and with healthcare workers for references and sources. Ask them to suggest several potential panellists. Be sure not to schedule too far in advance, in case the individual becomes too ill to participate. *In accordance with confidentiality policies, do not identify by name any speaker who is HIV-infected in written agendas or printed materials without his or her explicit permission.* Ask the referring agency or individual for suggestions on ways to contact panellists without compromising their anonymity. **Interview potential panellists in advance.** Interview panellists beforehand to ensure they will be able to comfortably and succinctly articulate the impact of HIV/AIDS on their lives. Assess whether the prospective panellists have central nervous system (CNS) symptoms—a PLWHA with confusion, depression, or poor concentration is usually not appropriate for a panel. PLWHA and family members who express a great deal of anger may make audience members and other panel members defensive or angry, preventing the group from achieving the purpose of the exercise.

APPENDIX 5-B Guidelines for PLWHA panels *(continued)*

Exercise 5.3 PLWHA Panel	
Instructions (continued)	**Budget for panel honoraria and expenses.** Whenever possible, pay panellists an honorarium and offer food, transportation, and child care reimbursement, as needed. If policy allows, be prepared to make payments in cash on the day of the panel workshop. Make sure to obtain a signed receipt from panellists. **Prepare the panel.** Make initial contact to assess the individual's willingness to participate in the panel. Provide information about the date, time, and objectives of the activity. About 3 to 7 days before the event, contact the panellists to see whether they have questions about the panel and to assess their physical health. Also discuss which issues they are planning to focus on and review concerns regarding anonymity (photographers, media presence).
	The facilitator's role is critical to the panel's success. The facilitator can: ▪ Arrange to meet with all panellists before the panel to help alleviate their anxiety. ▪ Review the format for the panel: time allowed for each presentation, when and how the audience will ask questions. ▪ Ask panellists how they would prefer to be introduced to the audience. Panellists may prefer to introduce themselves so they control how much identifying information they disclose. ▪ Be supportive. Assure panellists that they may refuse to respond to any question—at any time and for any reason. ▪ When the panellists are speaking, monitor time closely to ensure that everyone gets a chance to speak. Gently remind panellists when they are exceeding the time limit. ▪ Facilitate Q&A. ▪ At the end of the panel discussion, the facilitator should be available to provide panellists with support and to thank each panellist.
Adapted from Mountain-Plains Regional AIDS Education and Training Center. 1994. *HIV/AIDS Curriculum, 5th Edition*. Mountain-Plains Regional AETC: Denver, CO.	

APPENDIX 5-C Sample question guide to be used with PLWHA panellists

Directions: The following is a sample question guide to be used with a panel of people with or affected by HIV. This list covers extensive ground. Do not attempt to address every question.

Adapt this list to suit the focus and objectives of your panel and to the willingness of panellists to discuss a topic area. Delete unnecessary questions, highlight key questions, and add questions as necessary.

Share your question guide with the panellists prior to the day of the panel.

Please start by telling us about yourself, focusing on the history of your HIV infection.

1. Testing and counselling

- When were you diagnosed?
- What was it that made you go for the HIV test?
- How was the test result conveyed to you?
- How did you react after you were told that you were HIV-positive?
- What happened that night? How about later that week?
- What questions did you have during that first week?
- In retrospect, how can we improve our services to better anticipate the needs of people who are newly diagnosed with HIV?

2. Disclosure

- Who was the first person you told about your HIV status?
- What was the person's reaction?
- Tell us about other reactions you have received.
- Who has been supportive?
- Do you work? Were you working at the time you were diagnosed?
- If so, do they know you are HIV-infected?
- How did your supervisors and colleagues react?
- How did the healthcare system receive you?
- Tell us about the care you received.

3. HIV-related care

- How did the healthcare system receive you?
- Tell us about the care you received.

4. PMTCT

- If you could design a PMTCT service, what would you make sure was included?
- What is important about the staff we recruit?

APPENDIX 5-D Alternative exercise 5.3

This exercise is optional and may be used in settings where a PLWHA panel cannot be recruited.

Alternative Exercise 5.3 Stigma and discrimination: case study	
Purpose	To explore our own culturally-conditioned feelings and attitudes with respect to HIV/AIDS-related stigma and discrimination. To discuss any inadvertent breaches of confidentiality that may have perpetuated stigma and discrimination. To consider ways that we, as healthcare workers, can help combat HIV/AIDS-related stigma and discrimination.
Duration	90 minutes
Introduction	Explain that this exercise is a small-group discussion to explore the face of stigma and ways that we as healthcare workers may inadvertently perpetuate stigma.

Activities	▪ Separate participants into four small groups (ideally 3 to 5 people per group).
	▪ Distribute copies of the case study to participants.
	▪ Give participants approximately 15 minutes to discuss the case study, ask the small groups to reconvene as a large group.
	▪ Assign the following topic to the groups:
	  ▪ First group: discuss the issues of stigma and discrimination highlighted in the case study.
	  ▪ Second group: present ideas for ways PMTCT services can minimise stigma and discrimination.
	  ▪ Third group: discuss community-based initiatives that could be developed to reduce stigma and discrimination
	  ▪ Fourth group: consider national policy/legal changes that could be advocated
	▪ Ask the groups to reconvene; then have each summarize the primary points of their discussion. Ask the other groups if they have anything else to add.
	▪ Write the most important points on the flipchart.

Debriefing	Close the exercise by asking participants to consider what they can do to address HIV/AIDS-related stigma and discrimination in their homes, workplaces, places of worship, communities, and other settings. Tell participants they may answer aloud or keep their responses private.

APPENDIX 5-D Alternative exercise 5.3 *(continued)*

Case study

Two PMTCT nurses, Joan and Yvette, were in the ANC clinic break room. Their conversation evolved from the usual discussion about family and children into a discussion about Fay, a patient they saw earlier today. Joan and Yvette remembered Fay quite clearly from the morning clinic, maybe because she is such an attractive and outgoing woman or maybe because she was the first patient of the morning. They couldn't help but talk about the fact that Fay, who is now 5 months pregnant with her first child, was just diagnosed with HIV. Nor could they help speculating whether Fay's husband (who is well-known in the community) is also HIV-infected—and if he is, where he got infected.

The nurses were unaware that the window in the break room was open to the outside courtyard, where Eunice, an afternoon ANC patient, had excused herself and her mischievous toddler to wait for her appointment.

Eunice, who was related to Fay by marriage, went straight home after her appointment and told her husband about Fay's HIV diagnosis. The next day Eunice's husband told a friend at work who, a week later, mentioned the story in front of Fay's husband. Fay's husband went home that night, accused Fay of being HIV-infected, and asked her to leave the house.

Questions to consider:

- What about HIV/AIDS-related stigma and discrimination does this case study highlight? (eg, How was Fay stigmatised? How was Fay discriminated against and by whom?)
- What issues does this raise in terms of PMTCT policies? How can these policies help minimise stigma and discrimination?
- What policies should be in place?
- What training should be provided to ensure staff adherence to the policies?
- What else needs to happen to ensure that the policies are implemented and enforced?
- What barriers do you foresee?
- What community-based initiatives could be implemented to reduce the kind of stigma and discrimination faced by Fay and her husband (and, indirectly, her child)?
- Are any national policy/legal changes suggested by this case study? If so, what are they, and how would you go about ensuring it happens?